

Washington State Genetics Task Force
Subcommittee 4: Minority Opinion
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Summary

I strongly disagree with the taskforce's overall recommendation that no new legislation is required to protect the privacy and civil liberties related to genetic information in Washington State. While almost all taskforce members agreed that a person's genetic information is private and that all forms of discrimination based on genetic information should be outlawed, the main debate was over whether existing laws provide adequate protection.

The recommendation of the taskforce is not surprising consider its composition. The membership was heavily weighted with health care, research and insurance representatives whom seemed more concerned with the administration costs of dealing with new laws than with the protections provided to citizens under existing laws. The groups they represent would prefer to remain self-policing.

The taskforce members representing individual rights, including myself, do not accept the assumption that current laws that do not explicitly mention genetic information provide adequate protection. There is a patchwork of laws that cover genetic privacy when it is collected in a federally regulated health care setting, but those laws do not apply to other groups such as private researchers. Genetic information is sensitive information about individual – the laws protecting privacy of that person's information should not depend on who collects the information.

Over 45 other states have strengthened their laws to include additional protections related to genetic privacy and genetic discrimination. It is time that Washington State extend those protections to its citizens.

Subcommittee 4: Other Social Purpose (Insurance, Employment)

I disagree with the subcommittee's recommendation that existing laws are not required to prevent the use of genetic information in employment and insurance decisions. A majority thought that the ADA and RCW 49.60 provided adequate protection in employment, however neither law explicitly mentions genetic information. The group's assumption was that the courts would interpret the laws that way, even though it has not been tested.

Specifically Washington State should change RCW 49.60, the Law Against Discrimination, to explicitly include "genetic information" in the list of characteristics that receive protection under the law. As it is written, the law only explicitly protects discrimination based on "sex, race, creed, color, national origin, marital status, age or the presence of any sensory, mental or physical disability, or the use of a trained dog guide or service animal by a disabled person.

We should also amend the Uniform Health Information Act to define genetic information obtained as a result of participation in human subjects research be defined as medical information.